

**Introduced by Senator Steinberg**

February 21, 2008

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An act to add Chapter 9 (commencing with Section 104324.6) to Part 1 of Division 103 of the Health and Safety Code, and to add Article 17 (commencing with Section 18881) to Chapter 3 of Part 10.2 of Division 2 of the Revenue and Taxation Code, relating to amyotrophic lateral sclerosis (ALS).

**LEGISLATIVE COUNSEL'S DIGEST**

SB 1502, as introduced, Steinberg. Amyotrophic lateral sclerosis (ALS).

(1) Existing law makes various provisions for the prevention of disease, including chronic diseases, and the promotion of health, and requires the State Department of Public Health to implement and administer various health promotion and preventative health services.

This bill would declare the intent of the Legislature that it is in the interest of the state to better serve the thousands of persons with amyotrophic lateral sclerosis (ALS) and their families who are currently struggling with ALS or to care for a family member with ALS, that research for ALS remains the only real hope for an effective treatment and cure for persons with ALS and their families, and that this state should take the lead for a robust program of innovative and creative research for an effective treatment and, ultimately, a cure for ALS.

(2) Provisions relating to the administration of personal income taxes allow individual taxpayers to contribute amounts in excess of their tax liability for the support of specified funds.

This bill would additionally allow taxpayers to designate on their tax returns that a specified amount in excess of their tax liability be

transferred to the ALS Research Fund, which would be created by this bill.

This bill would provide that all money contributed to the fund pursuant to these provisions would be subject to appropriation by the Legislature, as specified.

This bill would provide that these voluntary contribution provisions are repealed on January 1, 2013. The bill would also provide that the provisions are repealed for taxable years beginning on or after January 1 of the calendar year in which the Franchise Tax Board estimates, by September 1, that the contributions made on returns filed in that calendar year will be less than \$200,000.

Vote: majority. Appropriation: no. Fiscal committee: yes.  
State-mandated local program: no.

*The people of the State of California do enact as follows:*

1 SECTION 1. Chapter 9 (commencing with Section 104324.6)  
2 is added to Part 1 of Division 103 of the Health and Safety Code,  
3 to read:

4  
5 CHAPTER 9. STATEWIDE ALS DISEASE AND RELATED DISORDERS  
6 RESEARCH POLICY  
7

8 104324.6. The Legislature finds and declares all of the  
9 following:

10 (a) Amyotrophic lateral sclerosis (ALS), often referred to as  
11 Lou Gehrig's Disease, is a progressive neurodegenerative disease  
12 that affects motor neurons in the brain and the spinal cord. On  
13 average, persons with ALS (PALS) die within two to five years  
14 of diagnosis.

15 (b) In the 150 years since ALS was identified as a disease, there  
16 is still no known cause, prevention, treatment, or cure.

17 (c) It is estimated that there are more than 30,000 Americans,  
18 including several thousand Californians, who have ALS and related  
19 disorders at any given time. Based on United States' population  
20 studies, a little more than 5,600 people in the United States are  
21 diagnosed with ALS each year. Approximately every 90 minutes,  
22 someone is diagnosed with ALS, and every 90 minutes someone  
23 else dies from ALS.

1 (d) Veterans are 60 percent more likely, and Gulf and Iraqi War  
2 Veterans twice as likely, to get ALS than the general population.

3 (e) Research has shown that coordinated and comprehensive  
4 community-based clinical care provided within a multidisciplinary  
5 treatment program can marginally extend life and improve the  
6 quality of life for PALS.

7 (f) ALS affects the PALS' family as the burden of care falls  
8 largely on them. In the later stages of the disease, this amounts to  
9 24-hour, seven-day-a-week regimen and the need for respite care  
10 for these caregivers. The costs of the disease escalates well into  
11 the six figures during this stressful and emotional period, often  
12 after a spouse, child, or other family member quits working to care  
13 for their loved one, thereby depleting family savings and resources.

14 (g) The incidence of ALS and related disorders in California  
15 will increase as the state's population of baby boomers ages.

16 (h) The surge in the numbers of those persons affected by ALS,  
17 including family caregivers, will place a severe strain on the state's  
18 already challenged health, social services, geriatric, and other  
19 service delivery systems.

20 (i) Advances in ALS disease research and promising ongoing  
21 clinical trials are testing agents that may slow progress of the  
22 disease, delay its onset, and some day prevent the disease  
23 altogether, as well as more effectively manage challenging  
24 symptoms.

25 (j) Genetics, toxic agents, and stress are all suspected as possible  
26 causes of the disease. However, further research is needed to  
27 determine whether any or all of these, or possibly other, factors  
28 are the cause or causes of ALS and related disorders.

29 (k) ALS Centers of Excellence, clinics, and centers and other  
30 entities have made significant contributions to the advancement  
31 of ALS disease research, and it is imperative for the state to have  
32 primary care and long-term care delivery systems that are  
33 positioned to utilize these research findings to improve care for  
34 PALS living with ALS and related disorders.

35 (l) While advances in ALS research create hope for the future,  
36 they will not head off the increasing need for community, home,  
37 and residential in-home and respite care that is equipped to care  
38 for PALS suffering from ALS and related disorders. In-home and  
39 respite care are nonexistent or woefully inadequate for PALS and  
40 their families.

1 (m) To help avoid bankrupting our health and social service  
2 systems serving Californians, California must prepare now by  
3 identifying strategies that will provide appropriate care to families  
4 coping with and caring for a family member afflicted with ALS.

5 (n) It is in the interest of the state to better serve the thousands  
6 of PALS and their families statewide who are currently struggling  
7 with ALS or to care for a family member with ALS.

8 (o) Research for ALS remains the only real hope for an effective  
9 treatment and cure for PALS and their families.

10 104324.61. (a) The System of Care for ALS in California,  
11 described in companion Senate Bill \_\_\_\_\_, including existing and  
12 future Centers of Excellence, and other entities have improved the  
13 quality of care available to the victims of ALS and increased  
14 knowledge with respect to ALS and related disorders. ALS is an  
15 insidious killer of thousands of Californians. It absorbs millions  
16 of dollars from California's economy through health care costs,  
17 and takes a tremendous toll on the personal lives of its citizens.

18 (b) In recognition of the fact that there is no known cause,  
19 prevention, treatment, or cure for ALS, and that research for ALS  
20 is the only real hope for an effective treatment and cure for PALS  
21 and their families, it is the policy of this state that California should  
22 take the lead for a robust program of innovative and creative  
23 research for an effective treatment and, ultimately, a cure for ALS.

24 (c) The Centers of Excellence described in companion Senate  
25 Bill \_\_\_\_\_ and other entities provide clinical opportunities for  
26 research and facilitate the collection of essential data regarding  
27 ALS, while at the same time providing valuable services, such as  
28 information and referral, counseling, and training to ALS victims  
29 and their families. ALS Centers of Excellence, postsecondary  
30 higher educational institutions, medical centers, hospitals, other  
31 medical facilities, research facilities, health care organizations,  
32 and private industry all should participate in research to discover  
33 the cause of, and ultimately a cure for, ALS.

34 (d) ALS research should encompass the cause, prevention, cure,  
35 diagnosis, and treatment of ALS, including, without limitation,  
36 research in the fields of neurology, biomedical science and  
37 engineering, economics, epidemiology, diet and lifestyle, public  
38 health and technology development, and translation. In addition,  
39 this program should provide for the systematic dissemination of  
40 research results to the public and the health care community, and

1 provide for a mechanism to disseminate the most current research  
2 findings in the areas of cause, treatment, cure, earlier detection,  
3 and prevention of ALS, in order that these findings may be applied  
4 to the planning, implementation, and evaluation of this program.

5 (e) The functions of the Centers of Excellence and other research  
6 entities described above should include all of the following:

7 (1) To increase research in discovering the cause of, and a cure  
8 for, ALS.

9 (2) To increase the training of health care professionals and  
10 researchers with respect to ALS and other acquired brain  
11 impairments to the extent that they have the requisite expertise.

12 SEC. 2. Article 17 (commencing with Section 18881) is added  
13 to Chapter 3 of Part 10.2 of Division 2 of the Revenue and Taxation  
14 Code, to read:

15  
16 Article 17. ALS Research Fund  
17

18 18881. The Legislature finds and declares all of the following:

19 (a) Amyotrophic Lateral Sclerosis (ALS), more commonly  
20 known as Lou Gehrig's disease, is a degenerative disease of the  
21 motor nerves that causes progressive weakness of all voluntary  
22 muscles. People with ALS become unable to move, swallow, speak,  
23 and breathe without assistance, usually remaining fully aware of  
24 what is happening to them and their families.

25 (b) ALS is a fatal disease. There is no cure and only one drug  
26 therapy, which allows the patient a month or two more of life.  
27 Most ALS patients die within two to five years of symptom onset.  
28 Every 90 minutes someone is diagnosed with ALS and every 90  
29 minutes someone dies of the disease. ALS knows no racial, ethnic,  
30 or socioeconomic boundaries, often striking people at midlife and  
31 at the height of family and financial responsibilities.

32 (c) The devastating physical, emotional, and financial effects  
33 caused by the progression of ALS and the 24-hour, seven-day-a-week caregiving required impacts not only the patient,  
34 but the entire family. ALS is a family disease and the need for  
35 research is dire.  
36

37 (d) It is the intent of the Legislature, in enacting this article, to  
38 establish a systematic program to conduct research regarding the  
39 cause, cure, and prevention of ALS. The outcome of this research  
40 may have direct effects and consequences on the development of

1 a comprehensive system that may identify the cause, cure, and  
2 prevention of ALS, as well as improving the screening, diagnosis,  
3 and treatment of victims of ALS. This program shall award grants  
4 to eligible physicians, hospitals, laboratories, educational  
5 institutions, and other organizations and persons for the purpose  
6 of enabling organizations and persons to conduct research.

7 18882. (a) Any individual may designate on the tax return that  
8 a contribution in excess of the tax liability, if any, be made to the  
9 ALS Research Fund, which is established by Section 18883.

10 (b) The contribution shall be in full dollar amounts and may be  
11 made individually by each signatory on a joint return.

12 (c) A designation under subdivision (a) shall be made for any  
13 taxable year on the individual return for that taxable year, and once  
14 made shall be irrevocable. In the event that payment and credits  
15 reported on the return, together with any other credits associated  
16 with the individual's account, do not exceed the individual's  
17 liability, the return shall be treated as though no designation has  
18 been made.

19 (d) The Franchise Tax Board shall revise the forms of the return  
20 to include a space labeled the "ALS Research Fund" to allow for  
21 the designation permitted under subdivision (a). The forms shall  
22 also include in the instructions, information that the contribution  
23 may be in the amount of one dollar (\$1) or more and that the  
24 contribution shall be used to conduct research relating to the cure,  
25 screening, and treatment of ALS.

26 (e) It is the intent of the Legislature that the 2008 tax return  
27 include a space for the ALS Research Fund.

28 (f) A deduction shall be allowed under Article 6 (commencing  
29 with Section 17201) of Chapter 3 of Part 10 for any contribution  
30 made pursuant to subdivision (a).

31 18883. There is in the State Treasury the ALS Research Fund  
32 to receive contributions made pursuant to Section 18882. The  
33 Franchise Tax Board shall notify the Controller of both the amount  
34 of money paid by taxpayers in excess of their tax liability and the  
35 amount of refund money which taxpayers have designated pursuant  
36 to Section 18882 to be transferred to the ALS Research Fund. The  
37 Controller shall transfer from the Personal Income Tax Fund to  
38 the ALS Research Fund an amount not in excess of the sum of the  
39 amounts designated by individuals pursuant to Section 18882 for  
40 payment into that fund.

1 18884. All money transferred to the ALS Research Fund, upon  
2 appropriation by the Legislature, shall be allocated as follows:

3 (a) To the Franchise Tax Board and the Controller for  
4 reimbursement of all costs incurred by the Franchise Tax Board  
5 and the Controller in connection with their duties under this article.

6 (b) To the State Department of Public Health, to provide grants  
7 for the conduct of research to physicians, hospitals, laboratories,  
8 educational institutions, and other organizations and persons.

9 18885. For the purpose of this article, “research” shall include,  
10 but not be limited to, expenditures to develop and advance the  
11 understanding, techniques, and modalities effective in the  
12 prevention, cure, screening and treatment of ALS.

13 18886. (a) Unless repealed earlier pursuant to subdivision (b),  
14 this article shall remain in effect only until January 1, 2013, and  
15 as of that date is repealed, unless a later enacted statute, which is  
16 enacted before January 1, 2013, deletes or extends that date.

17 (b) (1) By September 1, 2009, and by September 1 of each  
18 subsequent calendar year that the ALS Research Fund appears on  
19 a tax return, the Franchise Tax Board shall determine whether the  
20 amount of contributions estimated to be received during the  
21 calendar year will equal or exceed the minimum contribution  
22 amount. The Franchise Tax Board shall estimate the amount of  
23 contributions to be received by using the actual amounts received  
24 and an estimate of the contributions that will be received by the  
25 end of that calendar year.

26 (2) If the Franchise Tax Board determines that the amount of  
27 contributions estimated to be received during a calendar year will  
28 not at least equal the minimum contribution amount for the calendar  
29 year, this article is repealed with respect to taxable years beginning  
30 on or after January 1 of that calendar year.

31 (3) For purposes of this section, the minimum contribution  
32 amount for a calendar year shall be two hundred thousand dollars  
33 (\$200,000).

34 (c) Notwithstanding the repeal of this article, any contribution  
35 amounts designated pursuant to this article prior to its repeal shall  
36 continue to be transferred and disbursed in accordance with this  
37 article as in effect immediately prior to that repeal.